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ABSTRACT

This paper examines the issues of deinstitutionalization and mainstreaming from a historical perspective, focusing on the changes over time in views and practices toward retarded individuals and the role of science in the mental retardation field. The parallel development of residential programs and special education programs for individuals with mental retardation is described; and movements toward deinstitutionalization, normalization, and mainstreaming are examined. Excessive concern with the physical settings of services is cited, with the recommendation that the actual social and psychological characteristics within each individual setting be considered. The paper proposes that: (1) services should be matched to each person's needs, regardless of setting which might include the large institutions; (2) such large institutions should train new generations of professionals to work with retarded persons; and (3) large institutions which continue to be used should be humanized. Following the speech is a transcript of a question-and-answer period. It deals with the phenomenon of the decreasing numbers of children labeled as mildly mentally retarded, the state of the existing knowledge base in mental retardation research, and the need for regular education teachers to receive special training before mainstreaming occurs. (JDD)

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The Social Context of Research Design: From Theory to Practice in the Care and Education Of Retarded Individuals

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From Theory to Practice in the
Care and Education of Retarded Individuals

A pressing problem in the field of mental retardation is how to constructively intervene with and care for retarded individuals. There may be no issue or set of issues that is so beset with stridency, with polarized views, and with discoveries of "new" solutions. Though the current issues are complex, they are not new; nor are many of their purported solutions. Issues and solutions emphasized at any particular time often represent the swinging of the historical pendulum, whose path and speed are directed not only by the findings of scientific research, but also by political, economic, and social forces that often do not result in the clearest view of the problem.

Today I will address the issues of deinstitutionalization and mainstreaming from a perspective based on history. An historical perspective is important because a knowledge of the field's history can help us to prevent an overselling of present "solutions" to age-old problems. Over the years, we have become wary of people who declare that we need not examine alternatives, and distrustful of any select group of experts who claim they already know the single best solution through the exercise of their common sense. Experience demonstrates that common sense often proves to be more common than sensible. To quote George Santayana, "progress, far from consisting in change, depends on retentiveness. . . . Those who cannot remember the past are condemned to relive it." It is my hope that we in the mental retardation field can be guarded and realistic in what we promise; perfection will no doubt always evade us.

Before discussing the history of mainstreaming and deinstitutionalization, I want to alert you to several themes you will hear running throughout this talk. I already alluded to the first, that views and practices toward retarded individuals change over time. Consider for a moment the field's views toward special education. In a major textbook written over 20 years ago, Robinson and Robinson concluded: "the consensus of special educators today definitely favors special class placement for the mildly retarded." Two decades later, virtually all mildly retarded children are in mainstreamed classes. Yesterday's orthodoxy has become today's heretical view.

A second theme involves determining the role of science and scientists in the mental retardation field: Should scientists gather information to help others make informed choices, as opposed to advocating for retarded individuals? Should scientists make choices for retarded persons and their families? Can scientists draw firm conclusions concerning care and intervention, especially given the fact that fashions change? These are only some of the questions, and themes, of the history I will turn to now.

The historical vantage point from 1988 allows us to see in bold relief the errors of the past, and provides a clearer perspective for our own efforts in the future. In 1848, the first private facility designed specifically to care for retarded people opened in Barre, Massachusetts. It was followed two years later by the United States' first public facility in Boston, founded by Samuel Gridley Howe. This is now the Fernald State School in Waltham. By 1890, there were approximately 20 residential schools in 15 states. In the field of special education, New York City and

Cleveland first established school classes for "problem children" in the 1870s. Providence originated the first classes specifically designed for mentally retarded children in 1894.

A host of special services for retarded persons also began during this period. It was a time of general optimism concerning the advancement of the social, political, scientific, and moral qualities of humankind. This spirit favored the development of numerous social institutions and services, including schools for blind, deaf, and mentally ill persons, and the establishment of the professions of medicine, nursing, education, and social work. As Best noted, "Probably the world has never known, before or since, such a pouring out of sympathy for the afflicted of society, a more zealous resolve to speed their relief, nor a more ardent faith in the possibilities of education."

The founders of American "training schools"--as institutions for retarded people were then called--and others concerned with the education of retarded children were influenced by this 19th century belief in progress. In particular, they were excited by news of the so-called "physiological education" developed by Edouard Seguin in France. Yet as Seguin's ideas reached the United States, his most influential contribution to the training of retarded persons turned out to be his view of what he called "moral education." This notion disavowed inhumane therapies and harsh discipline. Instead, the goal of moral education was a loving relationship between the teacher and pupil and the gentle bending of the will of the retarded student to that of the teacher. Proponents of moral education believed that teaching

retarded children involved "reawakening" them into a normal human existence. In essence, Seguin's legacy was the expectation that retarded individuals could be made normal.

Of course this expectation proved too optimistic, and by the late 19th and early 20th centuries views about retarded people had changed completely. At this point the causes of retardation were thought to be primarily genetic. The popularity of newly-developed intelligence tests demonstrated the discouraging finding that even at such outstanding institutions as the Vineland Training School, intelligence levels of retarded residents were failing to improve. These factors led to the popular "legend of the feeble-minded" which, in the harsh words of Walter Fernald, characterized retarded people as:

> "a parasitic, predatory class, never capable of self-support or of managing their own affairs. They cause unutterable sorrow at home and are a menace and danger to the community. Every feebleminded person is a potential criminal, needing only the proper environment and opportunity for the development and expression of his criminal tendencies."

In fairness, it should be noted that this legend of the feebleminded was not universally accepted. Fernald himself expressed great disappointment over the lack of improvement of retarded persons on Goddard's Binet-Simon tests. He later conducted a study of the life status of 646 retarded children released from the Waverly facility. The findings of this study, showing that over half of the former residents had made at least a fair adjustment to life outside the institution, led to a

change in Fernald's views. He conceded that "We honestly believed that nearly all of these people should remain in the institution indefinitely, but the survey shows that there are bad defectives and good defectives, and that a few defectives do not need or deserve life-long segregation." Fernald deserves much credit for changing his mind when confronted with new evidence. He makes a fine model for those of us in the field today.

During the earlier period, when pessimism was rife regarding retarded people, advocates of eugenics managed to pass legislation in twenty-five states mandating the sterilization of retarded people. Given these misguided fears and beliefs about retarded people, it becomes more comprehensible, although not excusable, why large institutions were built far from populated areas and filled to capacity between the 1920s and the 1960s.

Turning to the history of schooling for mentally retarded children, we note that special education programs were initiated to remove the most difficult students from the regular class setting. Thus around the turn of the century, special classes included not only mentally retarded children, but delinquent, truant, and emotionally disturbed students as well. When their formal schooling was over, most retarded children were expected to enter institutions. In 1920, Ada Fitts, supervisor of special classes in Boston, stated that sending these children directly from school to the institution would "safeguard the public from inefficiency, unemployment, pauperism, vagrancy, degeneracy, and all the other social consequences of feeble-mindedness." Over the years, this negative stereotype of mentally retarded

individuals caused them to be treated as if all attempts to educate them were futile.

The establishment of the Council for Exceptional Children in the early 1920s proved to be a harbinger of changing attitudes and diverse approaches toward retarded persons. Even in the early years of the Council's life, it played an important role in advancing educational opportunities for retarded children. Unfortunately, the very optimism it inspired for treatment of these students also led to the expectation that special education could radically elevate their levels of functioning. In pursuit of this unrealistic hope, experts in special education advocated widely differing approaches to schooling for retarded people. Thus even in the early years of special education, the field was rife with uncertainty and controversy over what direction it should take.

By the 1950s, the public education system had begun to understand that most retarded students could support themselves after their school years. Thus, public schools took increasing responsibility for their trainable retarded students. They did so for several reasons. First, moderately retarded children were living longer. Many parents did not want to institutionalize their children because of the deplorable reputations of large facilities. Second, the newly formed Association for Retarded Children lobbied effectively. They produced position statements such as the Education Bill of Rights for the Retarded Child, adopted in October of 1953. This bill proclaimed the right of every retarded child to a "program of education and training suited to his particular needs," and gained many a sympathetic ear. Finally, the shift of educational policy-making from local school boards to state

agencies increased the opportunities for retarded children. As a result of this activity, enrollment in special education classes jumped from 5,000 in 1953 to 30,000 a decade later.

The 1960s and 1970s saw the pendulum swing back again to criticism of special education. Since special education classes were generally smaller and more individualized than regular classes, school systems often balked at their increased costs. In 1962, G. Orville Johnson reexamined a number of post-school follow-up studies and found it "paradoxical that mentally handicapped children, having teachers especially trained, having more money per capita spent on their education, and being enrolled in classes with fewer children and a program designed to provide for their unique needs, should be accomplishing the objectives of their education at the same or at a lower level than similar mentally handicapped children who have not had these advantages and have been forced to remain in the regular grades." In 1964, Samuel Kirk published a research review arguing that despite the rapid increase in special classes for mentally retarded children, "there is only sporadic research evidence which justifies this increase." And, as I will discuss in a moment, in 1968, Lloyd Dunn reviewed the literature and published a paper that seriously questioned both the efficacy of special classes for mildly mentally retarded persons and their widespread installation.

We see, then, parallel, though not identical histories in the residential and educational treatment of retarded persons. Both were outgrowths of 19th century views of progress, and both featured ambivalence about the aims, costs, and provisions of services. In addition, both have shared the overly optimistic and

overly pessimistic views about retarded individuals prevalent in society at large.

Just as institutions and special education have overlapping early histories, so too can their more recent histories be seen as similar. In particular, both share in the recent move toward normalization, a view that has its own historical and philosophical underpinnings.

Historically, the widespread deinstitutionalization movement in the United States began with a series of indictments of large institutions during the 1960s that shocked the American public. In 1966, Blatt and Kaplan published a book of photographs entitled Christmas in Purgatory that depicted the deplorable conditions in several large institutions. The photographs showed poorly clothed or naked residents, residents locked in rooms whose only view out was a rectangular piece of glass measuring 3 X 6 inches, and large, lonely dayrooms smeared with excrement on walls, floors, and even ceilings. The now-defunct Look magazine published many of the photographs. The ensuing public response was greater than to any previous piece in the magazine. Equally inhumane conditions at the Willowbrook facility on Staten Island in New York were exposed and widely publicized both by the visit of Senator Robert F. Kennedy and by the television journalist Geraldo Rivera. At the same time, advocacy groups such as the National Association for Retarded Citizens were effective in exerting pressure to change existing institutions.

Similarly in the field of special education, there were historical forces helping to bring about normalized placements of special needs children. The U.S. Supreme Court decided in Brown v.

Board of Education that racially segregated classrooms could not be "separate but equal," and this reasoning permeated the thinking of special educators. A series of court decisions ruled against special class placement for black and minority children. Finally, in an influential article in 1968, Lloyd Dunn argued that special class placements did not more effectively foster development in retarded children, and that these placements stigmatized and segregated special needs students. Dunn felt that contemporary educational technologies put to use in regular, mainstreamed classrooms would better serve retarded children. As in the case of the large institutions, then, a series of historical forces were at work to promote normalized placements.

Philosophically, the normalization movement originated in Scandinavia and spread to the United States. According to Nirje, normalization is based on the idea that each person has the right to experience a style of life that is normal within his or her own culture. Thus, retarded individuals should experience a normal rhythm to the day, such as getting up in the morning, eating meals at certain times, and going to bed at an age-appropriate hour. There should be a normal rhythm to the year, such as enjoying vacations and holidays. The life span should also be normal, such as moving from the world of school to the world of work. Under the original concept of normalization, all individuals should be allowed the right to participate in activities common to same-aged members of the society.

With Wolfensberger's influential book, however, the focus shifted from normalization of lifestyles to a normalization of services. Retarded and otherwise disabled individuals could best

be served only when the services themselves were normal. That is, services for retarded individuals should be the same as, and no more restrictive than, services available to the nonretarded population. Indeed, Wolfensberger and others have equated a normalization of services with the attainment of more normal lifestyles. Successful environments for retarded individuals are those that are most "like normal," not necessarily those that most facilitate the development and adaptation of retarded individuals. The recently developed PASS model, which evaluates the adequacy of living alternatives based on the degree to which they approximate normal living settings, is an outgrowth of Wolfensberger's view of normalization.

One significant effect of the theoretical shift from normalization of lifestyles to normalized service delivery involves the interpretation of the 1975 Education for All Handicapped Children Act. This law assures a "free appropriate public education" for all retarded children, no matter how impaired. Certainly the law is an important turning point in the education of retarded children. In practice, however, its provision that they be educated in the least restrictive educational setting has usually been translated into a regular class placement for most educable mentally retarded children.

Again, in theory, everyone agrees that retarded children should live as normal a life as possible. Landesman and Butterfield refer to this as the consensus over the goals of normalization. Whether mainstreamed classrooms provide the best educational opportunities for retarded children is another matter. As Susan Muenchow and I argued, the proof of mainstreaming lies in

its implementation. And in practice, findings are mixed. Educable mentally retarded children in special education and mainstreamed classes seem to perform equally on academic achievement. Mainstreamed students show higher social skills but are stigmatized by their nonhandicapped peers. Levels of racial segregation, another of Dunn's original reasons for promoting mainstreamed classes, appear about equal in the two settings. Further, the hope that EMR children will learn through imitation the appropriate social behaviors of their nonhandicapped peers seems not to have been realized. Gresham writes that without sufficient training, "there is little empirical evidence to suggest that integration of handicapped subjects into regular classrooms will result in beneficial modeling effects." In addition, the nature of the classes in which the mainstreamed child participates, the methods of teaching, and the type of social interactions that take place have all suffered from a lack of research. Thus, we have not yet come up with an unambiguous answer to the simple question of whether segregated or integrated placement is best.

Similarly in the institutionalization area, almost every study shows that at least some large institutions are less restrictive than are some smaller settings. Even across different large institutions, quality varies enormously. In comparing two large state institutions, Earl Butterfield and I showed that size was unrelated to the atmosphere. In the first institution, every effort was made to provide a homelike environment. Meals were prepared in the living units and eaten in small groups. The frequent social events were co-ed, and the atmosphere encouraged responsibility on the part of the residents. In the second

institution, social events were segregated by sex. Meals were prepared by staff, residents ate in a large central dining room, and emphasis was placed upon external control by the staff. Another example of striking differences in large institutions can be found in Burton Blatt's book, The Family Papers. He describes the Seaside Regional Center in Connecticut in these terms: "even though it serves as a residential facility for over a hundred people, it has not fallen into the mood of hopelessness and monotony or produced the attitudes of indifference and degradation that continue at large institutions." Landesman and Butterfield note that these variations across different facilities of the same type are significant, and are sometimes greater than differences observed between different forms of residential care. One must be more concerned with the specific conditions within the institution rather than the size of the institution per se.

There are other examples showing that the equation of normalized services and normalized lifestyles is far from perfect. At the Vineland Training School in New Jersey, for instance, staff have developed a group home that is specifically designed to serve clients with Prader-Willi syndrome. The home is replete with staff supervision and client participation in areas of food choice, preparation, and intake. Behavior modification techniques are used to control behavior problems. This so-called specialized treatment group home has produced reduction in both weight and behavior problems in Prader-Willi clients. At the same time, it is both restrictive and consciously specialized, showing that an improved quality of life is sometimes facilitated through non-normalized delivery of services.

The problem, then, is that we in the field are making social policy and individual case decisions on the assumption that normalization of services equals more normal styles of life for retarded individuals. Indeed, in testimony I gave before Congress in 1976, I described normalization as a banner in search of some data. Adherents of the normalization approach wave this banner more for the emotional catharsis it provides them than for its usefulness in prescribing appropriate living settings or educational opportunities for retarded individuals. If normalization means only that large institutions should be closed and retarded children mainstreamed, then more thought must be given to the normalization issue as it concerns a better way of life for retarded persons.

In attempting to get beyond the label of normalization, we must first acknowledge that too often, workers have been concerned only with the physical settings of services for retarded individuals. We have conceptualized institutions, group homes, special education and mainstreamed classes, only as places, not as places within which interactions occur. To use Bronfenbrenner's terminology, we have fallen victim to a "social address" model of the environment, one in which the only variable of importance is where the services are delivered.

A better strategy involves consideration of the actual social and psychological characteristics within each individual setting. In particular, we need specific knowledge about how each type of setting, and each example within each setting, influences those social psychological variables that impinge upon the person's everyday life. This is true whether a person resides in an

institution or, more commonly, in a community residence. For example, in order to optimize the development of retarded persons, we know that caretaker continuity from one or a small number of adults is important; that socially fulfilling interactions with friends and acquaintances must be encouraged; that the opportunity for enjoyable and stimulating activities and an appropriate physical environment must be provided. Yet only when we know the degree to which these basic human needs are provided to retarded people can we begin to make useful interventions, if they do become necessary. In short, we have been arguing the issues of normalization, deinstitutionalization, and mainstreaming at a much too simple level.

My proposal, then, is that the services provided for each retarded individual be matched to that person's needs, regardless of setting. As concerns residences, this proposal would allow a role for the large central institution. In the realm of education, it would allow a place for special education classes and special schools. In short, it is my hope that all settings be improved, that the effects of each be evaluated, and that we continue to work for the best setting for each retarded individual.

This suggestion is not really too lofty or abstract. Already workers are struggling with the appropriate role for each of several service delivery settings for retarded individuals. Led by Marie Crissey, Marvin Kivitz and Marvin Rosen, workers at Elwyn Institutes in Pennsylvania and the Vineland Training School are attempting to determine the appropriate role of the large central institution within a continuum of services. One of their suggestions is that the large institution could oversee a

centralized network of services to retarded persons throughout their lifespans. The institution could serve as an information and referral source to parents. It could provide short-term, long-term, and supportive care for retarded people of all ages, and could serve as a liaison to public schools, vocational workshops, hospitals, and other agencies serving retarded populations.

Second, large institutions could train new generations of professionals to work with retarded persons. As centralized facilities which coordinate a network of services, large institutions could give workers the opportunity to gain experience with retarded individuals who vary in age, diagnosis, and level of functioning. This teaching mission is one that institutions such as the Vineland Training School have historically performed.

The third suggestion involves the continued use of large residential facilities as a full-time living place for retarded people. Today residents of large institutions are mainly those who are the most severely retarded, multiply disabled, or who show maladaptive behaviors. Thus, there appears to be a continuing need for these facilities, at least for the present. Still, this possibility can only be entertained if progress occurs in making institutions more humane living settings. I am concerned that the size and isolation--bureaucratic as well as physical--of many of these institutions may make such reforms difficult. Still, the achievements of many workers in the field convinces me that institutions can work. In addition, if it is possible to humanize large institutions, several of their unique advantages could be exploited: the very self-contained nature of these facilities would allow relatively easy scrutiny to make sure that humane

standards of care are routinely met. As George Tarjan instructed some years ago, if there are several hundred people in one building or set of buildings, they're visible; abuses may be harder to conceal and people will advocate for the residents within. But when those same residents are split up, with six in one location and eight in another, they vanish from public view.

Another advantage of a large, well-run facility is that parents know the institution will be available for their child as they themselves get older. The child's lifelong security would be assured. In short, institutions would provide the benefits for families and their retarded children that Oliver Sacks describes in relation to hospitals for severely emotionally disturbed individuals:

> "Hospitals, state hospitals, are often seen as 'total institutions' in Erving Goffman's sense, geared mainly to the degradation of patients. Doubtless this happens, and on a vast scale. But they may also be 'asylums' in the best sense of the word, a sense perhaps scarcely allowed by Goffman: places that provide a refuge for the tormented, storm-tossed soul, provide it with just that mixture of order and freedom of which it stands in such need."

Thus, whereas the goal of the institution would remain the most normalized style of life as possible, a short- or long-term refuge for retarded individuals and their families would be maintained.

Likewise with regard to special education services, a range of alternatives must be maintained. In particular, we must remember that the Education for the Handicapped Act specifically declared that all disabled children should be educated with

nonhandicapped children to the extent possible. The word "mainstreaming" does not occur in the law itself, but is an outgrowth of the movement to normalize services. Many experts in the field have begun to express reservations about how common mainstreaming has become. The Kennedy Foundation is presently trying to call together a group of experts to take another look at the mainstreaming practice and to determine what sort of education is ideal for mentally retarded children.

Presently, the mainstreaming issue is clouded by the fact that it is based on political and philosophical justifications rather than on any scientific evidence regarding the best school placements for children with particular handicaps. We need more research work on specific problems, rather than attempts at political panaceas. In the words of one parent, these panaceas only guarantee every child an equal shot at a mediocre education. And as Gottlieb noted, an "appropriate education for mentally retarded children has not yet been developed."

Hopefully, this review of history has made explicit the essential tension many of us feel as scientists and practitioners in the mental retardation field. On the one hand, it is our duty to gather and evaluate information, to participate in our work as responsible scientists. Yet all too often, each side of the normalization debate has lapsed into an advocacy or apologist role vis-a-vis group homes or large institutions, or mainstreamed versus special education classrooms. This sort of dogmatism intrudes as well into professional advice concerning the best placements for each individual retarded person. Today families who institutionalize a member are made to feel inadequate or guilty,

and these are problems which can be as long-lasting and hurtful as the actual difficulties of dealing with a retarded loved one. Scientists such as ourselves, acting as scientists, have a clearly defined role: to obtain information by using our most sophisticated methodology, to give our information to people who need it, and to allow those people to make their own choices.

In a more general sense, we have a special responsibility not only to conduct research, but to advocate for better lives for retarded persons. Obviously, differences of opinion are to be expected, as workers have and will continue to disagree about these issues. Still, given their importance, our mission must be to improve all residential and educational alternatives, to evaluate the effects of each, and to advocate for the mentally retarded population, always with history, science, and humaneness as our guides. If fortunate, we as a discipline will contribute to bettering the lives of retarded persons, while simultaneously lessening our own stridency and polarization concerning the care and education of retarded individuals.

Edward F. Zigler -- FROM THEORY TO PRACTICE IN THE CARE AND EDUCATION OF RETARDED INDIVIDUALS

QUESTION & ANSWER SESSION

Q. I've always thought of mainstreaming and normalization more as statements of social values rather than statements of theories or theories that would lead to technologies. And I would have an interpretation of much of the same literature that you have gone through as being questionable, mostly from the point of fidelity of implementation. So I don't know that we have "a" definition of mainstreaming. I think mainstreaming is a desired outcome; perhaps that's what makes it a social value. I don't know that we have "a" definition of normalization that we can test in some ways, that people have implemented in some standardized fashion. I don't know what my question is, other than that I have a different view, I think, of normalization and integration, or mainstreaming, than you've presented in your talk today.

A. The fact is, you're right, and I don't think we're disagreeing about it. I believe part of the problem is that we really don't know what we're talking about when we use these terms. They haven't been carefully defined. Normalization can mean very different things to different people. Mainstreaming is not really a set practice but is a continuum. It seems to me these terms have become shibboleths rather than hard formulations. So your very question serves to underline what I consider to be one of the points of the address: although we're not really clear

what we're talking about, a lot of people continue to use the words. That's what I meant by saying that these are good banners, that they sound well, but what do they mean? The fact, though, is they have had real impact in the real world. On the mainstreaming front, there's no question that children who used to be in special education are now in mainstreamed classes. By the same token, moving to institutionalization (which I see as parallel), some years ago professionals routinely advised parents to institutionalize retarded children. Today, if a parent tells us, "I have to institutionalize this child--my family's going under," we consider that a kind of a loss for ourselves in some way--that we've failed, or they've failed. So, your question helps to underline what I've been trying to say. Another question.

Q. Ed, a number of people have been commenting on the disappearance of mild mentally retarded children. There seems to be fewer and fewer showing up now. And I just wanted to ask you if you agree that this is a phenomenon that is in fact occurring, and if it is, what are your thoughts on why.

A. I remember a few years ago, Jim, when you and I and some of our colleagues went to Sweden, at the request of the Kennedy Foundation. They were convinced that the rate of retardation in Sweden was 1/15 of what it was in the United States. You had one explanation for these numbers. My own was that if the identification process was done carefully, there were no

differences. I think that this notion that mild mentally retarded children are disappearing is--well, nonsense. My full view of this matter is contained in my recent book, Understanding Mental Retardation, written with Bob Hodapp. I continue to believe that the big bulk of the mildly retarded population simply represents the lower portion of the normal distribution of intelligence that's predicted from any polygenic model and from the gene pool. So the notion that we're ever going to see populations in which everyone is above the mean on some measure like an intelligence test has got to be nonsensical.

In the Zigler and Hodapp book we did a careful study of prevalence, and I think one of the more surprising outcomes of that analysis was contrary to the thrust of your question, Jim. I have argued, and now is the time to go on and test it, that in the United States today there are maybe up to a million children who are retarded but currently cannot be labeled as such. The polygenic model says that among parents with normal or even superior intelligence, through the process of polygenic mix, a certain number are going to have retarded children, just as two retarded parents can have a nonretarded child. I won't burden you with the genetic equations for this, but they are fairly simple. That says to me that we have a whole group of mildly retarded children in our society who have middle-class parents. Now take this case--you have a little boy in school who is not doing very well. You give him an I.Q. test and he scores 60.

Well, what kind of retardation is it? You look at the parents. Both parents are college graduates and are in the middle class. It can't be cultural familial retardation--he doesn't meet the criteria of AAMR on that. You look for organic causes and find none. What possible diagnosis could you give that child?

Not long ago when I was kind of at sixes and sevens, I asked my old friend, George Tarjan, "George, according to my analysis, there's got to be nearly a million of these children out there. I've never seen one case history of one such child. Do they exist? Have you ever bumped into any?" And George said, "Oh yes, Ed. We call that the Hollywood Syndrome." I said, "Why the Hollywood Syndrome?" He said, "Well, these are children whose parents really don't want the label mentally retarded, and they shop around until they get a label they can accept. And professionals help these parents in two ways." He calls them the physician bashers. These are M.D.s, usually pediatricians, who say offhandedly, "What happened is that when the child was born, there was some minimal brain damage." So the parents can live with that. The second way is to give them a a diagnosis they're comfortable with. Today the diagnosis of choice is "learning disabled." My hunch is that "learning disabled" is really a wastebasket category that is acceptable to parents who are shopping for a label that doesn't sound harsh or permanent. There are a lot of ways of testing this formulation, and I plan to do this over the next couple of years. But if I'm right,

there are probably way more mildly retarded children than we've ever recognized. Another question.

Q. I got from your talk the idea that our knowledge base in several critical areas is less well developed than it should be, even though research has been going on for ten, twenty years or longer. Why do you think that the knowledge base is not further along with respect to some critical issues in special education? What kind of obstacles have we faced? Are any of them different from what you would find in medicine or other complex areas? And what can we do institutionally, collectively, to improve that knowledge base in a reasonably quick period of time?

A. That's a good question, and I've given it quite a bit of thought because I feel somewhat guilty, especially when I have to face the young workers among you. Some of us who are Jim's age and mine are fortunate. We lived through what I consider to be the golden age of research in mental retardation. A lot of money, a lot of support, a lot of interest, and some very good theorists came along. Those were the years from about 1955 to 1970, when it ended pretty precipitously. You people here are one of the few remnants, thanks to the wisdom of the Office of Education. I guess I took the wrong side when I was a party to the big debate when we set up NICHD. There was some thought that we should have been an institute of retardation. I was one who argued "No, you'll understand retardation best by understanding normal human growth and development." Being in the winning camp

wouldn't have made me so happy if I knew that later on a director of NICHD would essentially cut MR research off at the knees. That's one of the few times I've taken up cudgels in print and argued against the director of NICHD by name.

Another group that I think has abandoned us (by "us" I mean researchers) is the National Association for Retarded Citizens. Many years ago I was the first and I guess only recipient of their award for scholarship in the social and behavioral sciences. They had one in medicine and one in our area. In addition to that, they used to give seed grants to young investigators. I was on the committee that would hand out this money--ten, fifteen thousand. You all know that when you're starting your research, this type of grant is very helpful. What happened has to do with normalization, what we've been talking about today. Once an organization thinks it has the answers and is ready to go on to advocacy, there's no reason to do any more research. If you truly accept a philosophic position, then why study any more. It essentially ends research. I'm afraid that's what happened to NARC. They became advocates for a position on which they felt very strongly. Not only did they give up their own research activities, but they essentially quit going up on the Hill to argue in behalf of research. When scientists like you and me go up and argue for money for ourselves, it appears very self-serving. When parents of retarded children

(represented by NARC) do it, it's not self-serving. So, we lost an avid supporter and ally.

I have great respect for what the Kennedy Foundation has done for many years. They used to have a research award and a meeting once a year. It gave the field status and made young people in the field feel that they were a part of something that somebody cared about. Today I see the Kennedy group doubling back to a research orientation. There are a number of these forces--including NARC and NICHD--that are beginning to come back. The Office of Education, starting way back in Jim Gallagher's days and continuing to the present, has stuck it out, so I don't want to paint too bleak a picture.

There's nothing very profound in my answer to you, Craig. You can't do this work with mirrors. It takes money; it takes forces that help us get the money. I don't see that money forthcoming until more of us stand up and say, "Hey, there's still a lot we don't know" and again assert that our practice can outdistance our theory and our science. We have not made that case to decision-makers in NARC. I'm not sure why. I will continue to try to do it, because the field of research historically has its ups and downs, and now is about time for an up. It was a very bleak field for many, many years before the '50s. Thirty years ago, there was a book that perhaps all of us should read because it was a classic in its time. It was called Mental Subnormality, published in 1958 by Masland, Sarason, and Gladwin. In that

book, my colleague and very close friend, Seymour Sarason, wrote that he found research in mental retardation to be wanting. He offered the explanation that people who are not too bright themselves are attracted to the study of retardation. Well, that was kind of a challenge for me. But just about the time he said that, we saw this tremendous upswing.

Just let me name some of the names. At that point in time we had only one theory, and it directed practice. We had the old Lewin-Kounin rigidity theory, which stated that by basic nature retarded individuals were rigid, that they loved to do perseverative things. So, what do you teach them to do? You of course teach them to do repetitive tasks over and over and over because it matches their basic nature. This theory explains why we were very reluctant to do any counseling, any therapy with retarded individuals--because the sine qua non of therapy is movement. And if someone is rigid you can't have movement, so why bother to work with retarded people.

In those days, if you knew who the Kallikaks and Jukes were and you knew how to give a Stanford-Binet, you were an expert in mental retardation. But then in very quick order, we had an infusion of money and concern because of the Kennedy family. A lot of historical forces came together at that time, and we produced a number of very intriguing theories. There was the Zeaman attention work, Spitz's cortical satiation research,

Luria's work in Russia, and on and on. I think most of those theories are wrong, but every theory is going to be wrong until the last person lives. That doesn't bother me. They were very exciting ideas. People were testing hypotheses that were theory-driven. I lived through that period, and it was wonderful. Those were the days, believe it or not, when people in Washington used to call you and say, "Hey, we've got money left over. Could you use a hundred thousand dollars?" I don't know if we did as well as we should have done at that time, but I've gone on too long. I've given you a twenty-year history which shows that things were very good, then they went sour. Are they going to turn good again? They'll only turn good to the extent that the entire field convinces decision-makers, "We really don't have the final answer. Let's continue to do some more work." That's been a theme of my talk today.

Q. One of the issues that we're seeing out in the field concerns many of the regular ed teachers who are involved in determining who goes into a special ed classroom or not. The Philadelphia public schools did a survey when they were seeing a ten-fold increase in the number of students being recommended for special ed, and they found primarily that the teachers were identifying these students based on behavior disorders. And the behavior disorder was basically disruptive of the learning process in the classroom. Whether they were in need of special services or not, the teacher determined they were interfering with what was going

on instructionally. It seems to me that right now the key ingredient, and perhaps you can respond to this, is the regular ed classroom teacher, who in many cases would be more than happy to see special ed classrooms come back in vogue again. They are telling us that they are overwhelmed by the demands placed on them; they point to the special ed teacher as having extra training, extra sources, extra support; and they look back on their own classrooms, where they're given very little. It seems to me that the teachers that we're interacting with are being overwhelmed.

A. I think that a group that has had the most headaches as well as the most negative impact has been the teachers in mainstreamed classes. I did a study in several communities in Connecticut to test the fairly simple notion that how much training a teacher has had in working with handicapped children would be related to how well these children were doing on various psychological measures after being mainstreamed. The results were astonishing. What I discovered was that the median number of courses that these teachers had is one. Half had zero--no contact whatsoever. I put the blame in Washington. One of the things that always interests me about Washington, and I have been running back and forth to this town for a good long while, is how the left hand never knows what the right hand is doing. Let me illustrate how mainstreaming in the public schools might have been handled to make it work.

I was one of the planners of Head Start in this country. Then when I was in charge of Head Start in the early '70s, I discovered something that we hadn't even thought about in 1965 when we began the program. Handicapped children were not allowed in America's Head Start program between 1965 and 1971. And I was the decision-maker who said, "Why aren't we enrolling handicapped children in Head Start? We know that the prevalence is much higher among the poor than it is anywhere else." Once I announced that I was going to admit handicapped preschoolers, I heard a terrible outcry from Head Start teachers. "We're doing all we can do now. These children who are not handicapped but who are poor are a trial and a tribulation. Now you want us to deal with handicapped children. There's no possible way we can do more." Well, what we did is put into place a gigantic national support system for those teachers. We gave them special training on how to deal with these children. We gave them people who would come and work with them in the classes--support services. Today in Head Start, 12 to 13 percent of all the children are handicapped. And there are no longer loud outcries by the teachers that they're being overburdened.

No such support was offered when the Education for All Handicapped Children Act was passed. Schools were given ten thousand pieces of paper to fill out, but only 7 percent of the money that it really costs to deliver the services that were mandated. And nowhere in that whole package can I find any

thought as to how to support a teacher who has never seen a mentally retarded child when suddenly one comes into her class. Some states have done better than others, but I think that's why you are seeing what you are seeing.

Assuming we have correct classification and careful diagnosis practices, I continue to be convinced that there are some children who are retarded and should be mainstreamed. It was always ridiculous for us to put children with I.Q.s of 70 or 65 in institutions, and some may not belong in special ed classes either. They really are just below the slow learners, as far as I'm concerned. But they do present special problems. You now have a more heterogeneous population to teach, which is always hellish for teachers. And those with behavior problems are like the proverbial squeaky wheels--they are going to get some grease. But what we are also seeing in our studies of mainstreamed children, which worries me, is the very quiet child whose adaptation is to simply blend in and never say a word. And of course, many teachers are happy to have such children in their classrooms since they create no problems. The real problem, however, is that the child just sits there, and time goes by, but that child is not being educated in any way.

Again, I go back to an experience we had in Sweden when Jim Gallagher and some other scholars and I went to look at what was going on there. The Swedish are really committed to

normalization, and if a child fails in school the teachers think they've failed. My own analysis is that about half of the children in Sweden who are retarded by psychometric standards never get labeled as retarded. That would be a failure to the teacher. But what happens to those children? They get socially promoted grade by grade by grade, and when they graduate they find themselves unemployable.

As much as we're against labeling, and we all know the negative side of labeling, we often forget the positive side. My old colleague, Nick Hobbs, in his book on the futures of children, sets up a dictum that I like a lot, which is: "Never label a child unless the label carries with it enough positive services to offset the negative consequences of the labeling." The Swedish children who were spared the MR label were also spared the special services that would enable them to make it in their adult lives. Fortunately, unlike America, the Swedish government maintains a mental retardation registry and offers listed persons necessary services throughout their lives. So unlabeled graduates can still go to the registry and ask, "Would you please call me retarded so I can get training to make me employable?" So, support for teachers and the effects of labeling are the kinds of issues that continue to confound us in our excursion into mainstreaming.

Q. Mine is more in the nature of a comment also. (Part of question was inaudible.) How can colleges and universities

better prepare teachers to keep students in classes, how can school systems support teachers so that everybody can stay in the regular classroom, and how can communities support and develop students within the community so that they can stay employed? (Rest of question was inaudible.)

A. You feel that way, but I ask you what is your ultimate criterion? I'm afraid too much of what we are advocating is based on what we would want for ourselves. If you look at the home for Prader-Willi individuals, run by the Vineland Training School in New Jersey, it has only P-W patients and some pretty restrictive policies. But those clients are doing much better. I think we have to re-evaluate the standards by which we say a practice is good or bad. To me, there are two issues. First, there is the issue of humane treatment. I don't need any research to say that what my old friend, Burt Blatt, took pictures of in institutions should never exist. There's a certain level of decent care that every human being has a right to. That's one issue. The second issue is that I don't think we ought to be making policy on what makes us feel good. It ought to be made on what makes the quality of life for retarded people as high as it can be as they see it, not as we see it. I think every human being has a level of functioning that can be optimized at any I.Q. level. So in my own work, I continue to look at certain characteristics that I know make for a more

effective life. Those are my ultimate criteria for whether a practice is good or bad.

It's this kind of disagreement that my talk this morning was meant to bring about. I'm asking all of you to say, "Hey, why do you believe one thing rather than another thing? What's the evidence that you're using?" And as much as I respect your feelings, I don't think we can build a consensus on that basis, because everybody has different feelings. I would like to see our science based on something a little more empirical and data-driven than that. I think we should quit at this point.

M. Kaufman: Ed, thank you. The discussion that we're having, which is along the line of a standard of objectivity, going from an empirical line of objectivity to personal objectivity to getting consensus for the basis for objectivity, will thread itself through, I believe, the various discussions during the next day and a half. At this point we're scheduled for a break and then to your respective meeting rooms for the small groups. Thank you.